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Letting go

Editorial note

This article reflects part of Dr Twycross' lecture *Death without suffering?* given in October 2008 at the 2nd Congress of the Polish Association for Palliative Medicine. Much of the content will also be included in *Symptom Management in Advanced Cancer* 4th edition 2009, co-authored with Andrew Wilcock and Claire Stark Toller, whose contributions are gratefully acknowledged.

The article supplements those published in this journal (vol. 7, no. 3) on the need for a balanced approach in relation to the issue of sustaining life versus allowing death, and the need to avoid overzealous life-sustaining treatment in those with end-stage disease. The article has added value in that it is contributed by someone whose medical career, spanning some 40 years, was spent almost entirely in palliative care.

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Introduction

Society's commission to healthcare professionals is succinctly summarized in the aphorism "to cure sometimes, to relieve often, to comfort always". The same mandate applies in palliative care, even though the possibility of cure is limited to intercurrent events or complications such as infection. Given that the primary disease is incurable, the emphasis shifts decisively to relief and to comfort in end-stage disease.

Medical ethics and palliative care

Because there is an imbalance of power in the relationship between a professional and a client, professional behaviour is governed by ethical codes of practice. In this way, it is hoped that abuses of professional power can be avoided. In medical care, the same cardinal principles apply "across the board", from obstetrics to geriatrics, and from acute care to palliative care, namely:

— respect for patient autonomy (patient choice);

- beneficence (do good);
- non-maleficence (minimize harm);
- justice (fair use of available resources) [1].

These four principles are applied against the background of respect for life and an acceptance of the ultimate inevitability of death [2]. Thus in practice, there are three dichotomies which need to be held in balance:

- the potential benefits of treatment versus the potential risks and burdens;
- striving to preserve life but, when the burdens of life-sustaining treatments outweigh the potential benefits, withdrawing or withholding such treatments and ensuring comfort in dying;
- individual needs versus the needs of society.

There is also need for a sense of urgency, both in acute care and in palliative care. Thus the Emancipation Principle of palliative care:

No efforts should be spared to free dying persons from unbearable suffering which invades and dominates their consciousness, and leaves no space for other things [3].

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Patient autonomy

Doctors often act as if patients have an obligation to accept medically recommended treatment. However, legally a person is not obliged to accept medical treatment, even if refusal may result in an earlier death [4, 5]. Doctors thus have an obligation to discuss treatment options and their implications with patients, and to obtain their informed consent before proceeding with treatment.

Without consent, a doctor risks being found liable in battery [6]. If a patient lacks capacity to give or withhold consent, a doctor's legal obligation is to treat in what he perceives as the patient's best interests [7]. Severe depression, delirium (acute confusional state) or dementia are common causes of lack of capacity to give consent.

Principle of double effect

The principle of double effect has been described in various ways [8–11]. In essence the principle states that:

A single act having two possible foreseen effects, one good and one harmful, is not always morally prohibited if the harmful effect is not intended and there is no other way of achieving the same result.

The principle is generally ascribed to Thomas Aquinas, the 13th century theologian and philosopher [12]. It was originally enunciated in relation to self-defence. If I defend myself when attacked and my attacker is severely injured or killed, I can invoke this principle in my defence against a charge of grievous bodily harm or homicide. The principle of double effect is thus a universal principle which is invoked to exculpate someone when a good action results in unintended harm. The practice of medicine would be impossible without such a principle. It is essential because all treatment has an inherent risk and, inevitably, things sometimes go wrong.

Discussion of the principle of double effect often focuses on the use of morphine or similar drugs to relieve pain in terminally ill patients. This gives the false impression that the use of morphine in this circumstance is a high-risk strategy [13]. When correctly used, morphine (and other strong opioids) are very safe drugs, almost certainly safer than non-steroidal anti-inflammatory drugs. The use of both classes of analgesic is justified on the basis that the benefits of pain relief far outweigh the risk of serious undesirable effects. Indeed, clinical experience suggests that those whose pain is relieved live longer than would have been the case if they had continued to be exhausted and demoralized by severe unremitting pain.

However, the intended aim of treatment must always be the relief of suffering and not the patient's death. Although a greater risk is acceptable in more extreme circumstances, it remains axiomatic that effective measures which carry less risk to life or of harm should normally be used. Thus, in an extreme situation, although it may be ethically acceptable to heavily sedate a patient with drugs into unconsciousness (because less extreme measures have failed to bring relief), it is still generally considered unacceptable to precipitate death deliberately by administering a lethal injection (euthanasia).

Appropriate treatment

However, to achieve an appropriate balance between "fighting for life" and "allowing peaceful death", doctors must constantly keep in mind the undeniable fact that, ultimately, all patients must die. Thus, part of the skill of medicine is to decide when to allow death to occur without further impediment. A doctor is not obliged legally or ethically to preserve life "at all costs" [14]. Priorities change when a patient is clearly dying. There is no obligation to employ treatments if their use can best be described as prolonging the process of dying [15, 16]. A doctor has neither a duty nor the right to prescribe a lingering death. In palliative care, the primary aim of treatment is not to prolong life but to make the life which remains as comfortable and as meaningful as possible.

Further, because there is an ethical imperative incumbent upon health professionals collectively to ensure continuity of care, it should never be a question of to treat or not to treat. Rather, the question should be reformulated in terms of *what is the most appropriate treatment given the patient's biological prospects and his personal and social circumstances?* Appropriate treatment for an acutely ill patient may be inappropriate in the dying (Figure 1 and Figure 2). Nasogastric tubes, IV infusions, antibiotics, cardiac resuscitation, and assisted ventilation (and many other medical interventions) were all introduced into medical practice primarily as support measures for use in acute or acute-on-chronic illnesses to assist a patient through the initial crisis towards recovery of health. The use of these measures in patients who are irreversibly close to death is generally inappropriate, and therefore bad practice; the overall burdens (personal, social, financial) of such treatments exceed their potential benefits, and they are (or become) increasingly futile.



Figure 1. A graphical representation of acute illness. Biological prospects are generally good. Acute resuscitative measures are important and enable the patient to survive the initial crisis. Recovery is aided by the natural forces of healing: rehabilitation is completed by the patient on his own, without continued medical support

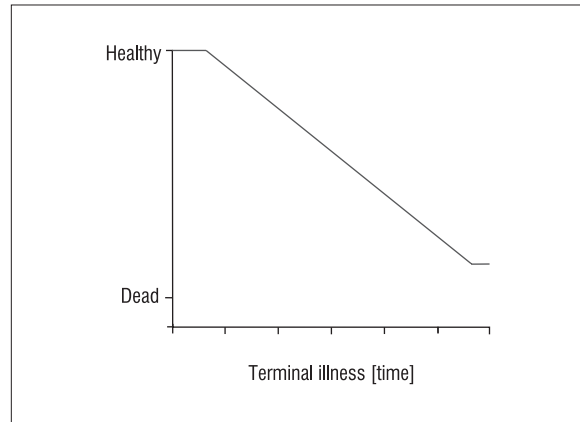


Figure 2. A graphical representation of terminal illness. Biological prospects progressively worsen. Acute and terminal illnesses are therefore distinct pathophysiological entities. Therapeutic interventions which can best be described as prolonging the distress of dying are futile and inappropriate

Thus, therapeutic recommendations are based on a consideration of the possible advantages (benefits) and disadvantages (risks and burdens) which might accrue for the patient. A doctor is not a technician and, in practice, there are generally several courses of action which might legitimately be adopted. Arguments in favour of a certain treatment revolve around the question of the anticipated effectiveness of intervention. Linked with this are considerations of the consequences and implications for the patient, the family and society as a whole. In other words, the doctor seeks, on the basis of the biological and social facts at his disposal, to offer the patient the most appropriate form of care, heavily influenced by what is perceived to be the patient's likely prognosis. Because death is inevitable for everyone, doctors ultimately have no choice but to "let nature take its course".

Medical care is a continuum, ranging from complete cure at one end to symptom relief at the other. Many types of treatment span the entire spectrum, notably radiotherapy and, to a lesser extent, chemotherapy and surgery. It is important to keep the therapeutic aim clearly in mind when employing any form of treatment. In deciding what is appropriate, the key points to bear in mind are:

- the patient's biological prospects;
- the therapeutic aim and benefits of each treatment;
- the undesirable (adverse) effects of treatment;
- the need not to prescribe a lingering death.

Although the possibility of unexpected improvement or recovery should not be totally ignored, there

are many occasions when it is appropriate to "give death a chance". Further, as death draws near, interest in hydration and nutrition often becomes minimal, and it is inappropriate to force someone to accept food and fluid. The patient's disinterest or positive disinclination is part of the process of letting go.

Case history

A 96-year-old woman with advanced Alzheimer's dementia was admitted to hospital because of suspected pneumonia. She had been bed-bound for 2 years, and had several decubitus ulcers. For many months she had not been able to speak and no longer recognized her sister (her main carer at home). In the past she had had a feeding gastrostomy inserted. She was treated vigorously with IV antibacterial and antifungal antibiotics for more than 2 weeks. Her sister then requested that the patient be discharged to her home, and allowed to die. This caused consternation ("an ethical crisis") among the doctors because, if she went home, it would not be possible to continue IV antibiotics and hydration.

This case history illustrates the fact that some doctors still practice medicine on the blinkered basis of delaying death "at all costs". The woman was being treated with very expensive antibiotics, costing several hundred euros per day. But to what purpose? It seems that the doctors had failed to think through the implications of dementia as an incurable progressive disease. The inappropriate treatment probably began some 2 years earlier when the patient could no longer feed herself, and no

longer accepted food from her carers (and probably actively clenched her teeth to prevent feeding). Then, instead of accepting this as part of a natural “shutting down” process typical of advanced dementia, they had intervened with a death-prolonging feeding gastrostomy*. Now, when the patient developed an aspiration pneumonia, instead of seeing this as another typical end-point in dementia, inappropriate and extravagantly costly measures were initiated. But, to what purpose?

I suggest that such interventions are best described as “mindless” or “meddlesome” medicine — treatment to be regarded as prolonging the process of dying rather than sustaining meaningful life. Unfortunately, the doctors involved had not fully integrated into their clinical practice the fact that ultimately all human beings must die. As a result, death is allowed only after weeks of intensive (and very expensive) acute care. Yes, they were presented with an “ethical crisis” — but it was one of their own making. It would have been much better if, long before this final admission, they had accepted reality, offered palliative (comfort) care pro-actively, and allowed natural death to proceed without further medical impediment.

Ordinary vs. extraordinary means

The concept of ordinary and extraordinary measures was first formalized in the 16th Century [17]. Ordinary measures are traditionally described as those which are not particularly burdensome. Thus, they:

- are financially affordable by most people in that locality;
- do not cause excessive or prolonged suffering for patients;
- have a good chance of success.

In contrast, extraordinary measures are those which are burdensome, or potentially so. Thus, they:

- are expensive;
- may result in severe adverse consequences, e.g. paralysis or a fistula;
- have only a small chance of success [18].

The concept may be useful for theologians advising people about what forms of medical treatment they should feel obliged to accept but, as demonstrated above, it is not the focus of the doc-

tor’s decision-making process. This is implicitly recognized by the increasing use of terms such as “proportionate” and “disproportionate”, and of “futility”. Such terms reflect an increasing acceptance in practice of the need to allow natural death in end-stage disease [19]. However, as the case history above illustrates, collectively, the medical profession still has a long way to go.

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*The author presents the problem of feeding in dementia in a controversial way. His article has provoked lively discussion among physicians in Poland and other countries. We have asked some authorities in the field of psychogeriatrics, feeding and metabolism and palliative medicine for their comments, which we plan to publish in the 2nd issue of *Advances* in 2010 (editorial footnote). Unfortunately we have not received on time the expected comments and articles, thus the publications will be included in one of the future editions of *Advances* (from editor).